

**NATIONAL EYE HEALTH EDUCATION PROGRAM  
OLDER ADULT NEEDS ASSESSMENT  
FOCUS GROUPS REPORT**

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## **I. OVERVIEW OF FOCUS GROUP OBJECTIVES**

The National Eye Institute (NEI) is interested in receiving feedback from older adults and older-adult health service providers to ascertain what information and materials are needed to improve the system of care for vision health among older adults. In doing so, the NEI queried older adults and older-adult health service providers about their knowledge of specific eye diseases and disorders that typically affect persons ages 65 and older; educational materials needed to increase their knowledge of age-related eye diseases and disorders; and the best methods for distributing materials to older adults and older-adult health service providers. The objectives of this study were as follows:

- To determine what older adults and older-adult health service providers know about age-related eye diseases and disorders.
- To determine what information in terms of age-related eye diseases and disorders is needed by older adults and older-adult health service providers.
- To determine the best method of distributing educational materials to older adults and older-adult health service providers.

## **II. STRENGTHS AND LIMITATIONS OF QUALITATIVE RESEARCH**

Data collected from focus groups and other sources of qualitative research cannot be generalized to a specific population. A focus group is not a statistically significant representation of a population. However, it consists of a group selected from the population being studied, and it can be used to learn topics of concern to that population. It is imperative that the interpretation of qualitative data not be misrepresented in quantitative terms. For example, a statement that “9 of 12” participants concur on an issue within a focus group should not be understood as “75 percent of the population of Anytown, USA.” Qualitative data may not be aggregated or quantified to characterize a population as a whole.

Identifying issues of concern to certain populations is one of qualitative research’s strengths: This research can also be used to formulate questions that can be answered by obtaining quantitative data. As the results of this study will indicate, focus groups often identify topics of concern that researchers may not have considered earlier, or they may suggest that the researchers need to restructure the questions.

## **III. METHODOLOGY**

### **Make-up and Recruitment of Groups**

In the summer of 2001, ORC Macro worked in conjunction with researchers from Johns Hopkins University to determine the prevalence of eye diseases among the various racial and ethnic groups in the United States. The results of the conducted research were published in the *Vision*

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*Problems in the US* report. To obtain qualitative data specifically from the older adult population, the prevalence data included in the report were used to determine ideal focus group sites by identifying cities with the highest prevalence of age-related eye diseases and disorders. Cities with the highest number of older adults were cross-referenced with cities identified as having high prevalence rates of eye diseases and disorders. Cities with the highest number of older adults and eye diseases were selected as sites.

Site selection also took into consideration race and ethnicity since certain eye diseases and/or disorders affect members of specific racial and ethnic groups more than others. The make-up of each older adult population focus group was exclusive to one particular racial and/or ethnic group to assess possible vision health care needs that may be unique to the respective populations.

Service provider groups comprised general health care workers who serve the targeted racial and/or ethnic group within the geographic location. The focus group participants represented the following professional and non-professional occupations: certified nursing, internal medicine, pharmacology, physical therapy, nursing care, home oxygen coordination, diabetic education, and parental care. However, this list is not comprehensive.

The research team developed a screener and provided it to professional research facilities that were subcontracted to recruit for focus group participants. (See appendix A). Professional recruitment applied to all sites, except Oklahoma.

To recruit for the American Indian focus groups, alternative recruitment methods were employed. The older-adult American Indian focus group that was conducted in Oklahoma was recruited from the Osage Nation. Using ORC staff contacts, a letter requesting permission to conduct a focus group was sent to the tribal council. Once approval was granted, two staff members conducted the focus group on the reservation. Video recording was omitted at the request of the tribal council.

Final site selection included the following geographic locations: Sioux Falls, SD; Chicago, IL; Boston, MA; San Francisco, CA; Portland, OR; Kansas City, MO; Tulsa, OK; and Minneapolis MN. Table 1 below illustrates the breakdown of focus group participants by geographic location and racial/ethnic representation. Sites are listed in the order that the focus groups took place.<sup>1</sup>

**Older-Adult Needs Assessment Focus Groups  
By Location and Race/Ethnicity**

	Sioux Falls, SD	Chicago, IL	Boston, MA	San Francisco, CA	Portland, OR	Kansas City, MO	Tulsa, OK	Minn., MN
African American/Black			X			X		
Asian American				X*				
American Indian							X	X*
Caucasian	X				X*			
Hispanic/Latino		X*						

<sup>1</sup> Table cells containing an asterisk (\*) indicate that at least one service provider focus group was conducted in that location.

## **IV. MODERATOR'S GUIDE**

The moderator's guides developed under this task were designed to obtain feedback from participants regarding the types of materials needed to educate older adults and older-adult general health service providers on age-related eye diseases and disorders. Both moderator's guides are attached in Appendix B.

The moderator's guide used for the older-adult population focus groups began by asking participants about their general health. The guide proceeded to ask participants about their overall knowledge of age-related eye diseases and disorders. However, prior to asking about specific eye diseases and/or disorders, the guide asked participants about their individual eye health care behaviors. The latter part of the older adult population moderator's guide queried participants about their resource needs in terms of vision health educational materials.

The moderator's guide for the health care providers was similar to the moderator's guide for the older adult population. Questions included in the health care providers moderator's guide specifically asked service providers about the older adults whom they serve. More specifically, the health care providers moderator's guide asked participants about general and vision health-related concerns that they typically hear from their patients or clients, their general knowledge of age-related eye diseases and disorders, and the resource materials needed to educate themselves on age-related eye diseases and disorders.

## **V. FINDINGS**

### **A. GENERAL HEALTH**

Overall, the majority of focus group participants said that they felt pretty good or great. Many of the participants mentioned specific ailments, but insisted that they felt good despite their respective illnesses. Common ailments mentioned by participants included, but are not limited to, arthritis, cancer, diabetes, high blood pressure, and high cholesterol. A few of the participants mentioned that they recently had cataract or heart bypass surgeries. Very few of the participants said that they feel bad or terrible.

*"I'm coming out the backside of lung cancer. (I still have one more chemo session) to do and a little problem with my white (blood cell) count. Generally, I'm in pretty good shape." (Sioux Falls, SD)*

*"I'm feeling good. I (had) a triple bypass." (Sioux Falls, SD)*

*"I guess my health could be a little bit better, but I feel terribly good. I had a heart attack (in) 1992, and I just got out of the hospital a month ago. I had an aneurysm. I'm on a lot of medication. I've got Addison's Disease... Now, I'm on a lot of steroids, but I feel good." (Sioux Falls, SD)*

*"Well, I say I'm good. Just good. Not very good because it hurts to walk from my arthritis. Other than that, I'm doing fine." (Chicago, IL)*

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*“Mine is good with limitations. I have a pacemaker. Other than that, (I’m) fine.”*  
(Chicago, IL)

*“I guess I’m pretty good. I have high cholesterol (and) high blood pressure, (but they’re) under control.”* (San Francisco, CA)

*“Well, I guess I got a lot of things wrong with me. I guess. I (have) cataract, high blood pressure, and diabetes. That’s about all, I guess. I feel good.”* (San Francisco, CA)

*“I’ve had three heart attacks, three open-heart surgeries, cancer, and diabetes. But I feel great.”* (Boston, MA)

*“I feel fine. In June, I had a major colon operation. I have 27 staples across the stomach. I’m fine. I’m 75. I ain’t got a care in the world.”* (Boston, MA)

*“I have arthritis, I’m overweight, and I have high blood pressure. But those problems, I try to work on. So, (on a) 1-10 (scale), my health is probably 7.”* (Kansas City, MO)

*“I have had two lung surgeries. I’ve had the left lower lobe on the right side removed, and the upper on the right side. So, I have kind of a breathing problem. But other than that, I’m fine.”* (Kansas City, MO)

*“I’m in pretty good shape. My legs don’t work too good. Got glaucoma. I’ve had cataracts and laser surgery on my eye. I don’t see too good.”* (Tulsa, OK)

*“I have had surgery in both eyes. I have implants, and I have had laser surgery. As for general health, I feel great and I have 20/20 vision so far.”* (Tulsa, OK)

### **B. TYPES OF HEALTH ISSUES FREQUENTLY HEARD**

Overall, service providers said that the most frequently heard health issues were arthritis; depression; payments for medications; poor nutrition; and hearing, sight, and memory loss. Other non-health issues mentioned included loneliness, cost of living, and quality of life.

*“People who are very vision dependent for the enjoyment of life can get, you know, really terribly clinically depressed when they can’t read anymore and they have trouble seeing the television, they have trouble navigating outside. And it’s really very, very profound, the impact it’s had on their lives.”* (San Francisco, CA)

The cost of prescriptions was brought up frequently as a health-related concern. As one health care provider in a Chicago focus group clearly stated, “(How to pay for) prescription drugs is the biggest problem.” Another participant in a Chicago focus group said the same. “Another big problem (is) medication. Many (older adults) cannot afford it.” The same sentiment was further expressed during a San Francisco focus group.

*“...And when I think about vision loss, for instance. Medicare doesn’t cover low vision specialist exams and it doesn’t cover a lot of the adaptive aids that people with vision loss may have. So, that whole issue of how are you going to pay for your health care needs... That’s primary.”*

Transportation was also brought up as a health-related concern among older adults. Apparently, many older adults are unable to access medication as they do not have friends or family who are able to take them to a local pharmacy. One health care provider in the Chicago focus group said, “sometimes they just aren’t able to get the medication, so they stop taking it because they weren’t able to get it.”

A couple of participants in the Chicago focus groups said that too many prescription medications are another prominent problem among older adults. For example, one health care provider said, “they’re taking more than a handful of medication each time.” Other participants concurred and explained,

*“Many patients complain they are on too many medicines. They will tell you that. Frequently, it can be started by, not just their internists, it could (also) be started (during) a hospitalization. Nobody knows why they’re on it.”*

*“When they come in the (emergency room), they have the whole bagful of drugs, and you’re trying to figure out why they’re taking both of these when they’re doing the same thing. So, a lot of times, they’re overmedicating themselves.”*

### **C. FREQUENCY OF DOCTOR’S VISITS**

When asked how often they visit the doctor, responses from the older adult population greatly varied. While the majority of participants responded that they visit the doctor every three to six months or once a year, other participants said otherwise. For instance, a participant in one of the African American focus groups conducted in Boston stated that he/she visits the doctor every two weeks. On the opposite end of the spectrum, another participant in one of the African-American focus groups conducted in Kansas City said that he/she has only visited a doctor four times in the past 10 years. Another participant in the group said, “...two years ago was the first time (I’ve) ever been to a doctor.”

This behavior was often observed during the African-American focus groups. Participants said that they understand the importance of getting regular check-ups. In fact, one Boston focus group participant said, “you know what they say about black men and the doctor—we need to go.” However, a general fear of doctor’s visits was evident.

*“Since I had colon cancer, they expect (me) to come back every so many years. I did at the beginning, but I haven’t been for such a long time... I know I’m wrong for doing that. They’re trying to take care of me. But it’s just my own feeling’ that I’m feeling too good for them to mess around with me... I just don’t want it. I’m feeling so good.” (Boston, MA)*

Another participant in the same focus group said that he/she could identify with the fear expressed by the participant.

*“I was thinking about what she was saying about they may find something. I went to the doctor (because the doctor needed) to check my throat and my breathing... They thought I had cancer of the throat. (Later), they found out all I had was pneumonia. They had*

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*checked me in (for) cancer. Every month I was going for this cancer they were talking about, and I didn't have it." (Boston, MA)*

Although a distrust of doctors was not common in the other focus groups, a Hispanic participant from a Chicago focus group explicitly stated that he did not trust doctors either.

*"I don't trust doctors because they give you some medicine and the medicine will do good now, but it's affecting something else... I kind have lost faith in doctors..."*

### **D. SOURCES OF HEALTH ISSUES INFORMATION**

Overall, the majority of focus group participants said that they do not use the Internet as a source for health-related information. However, participants that do utilize the Internet, a Google-type search on a particular disease and/or alternative medicine was conducted. Kaiser Permanente, WebMD, and the National Institutes of Health (NIH) were three of the Websites that were specifically mentioned. Other participants said that they ask a family member to conduct the search for them when they do want health-related information from the Internet.

Several participants in the Sioux Falls, Kansas City, and San Francisco focus groups mentioned that they often refer to the newsletters produced by the Mayo Clinic and the AARP for health-related information. A couple of participants voiced their opinions concerning the amount of health-related information that they receive from various organizations. One Chicago focus group participant commented, "usually when you hit 65, (organizations) are always bombarding you with stuff."

Some focus group participants relayed that they get information pertaining to health issues from the television or directly from their respective doctors. However, very few participants said that they receive written information of any type. The provision of verbal information was common among the Tulsa older adults. Other sources of health-related information included news magazines, church organizations, the Veteran's Administration, and the television and radio news. Several older adults in the Tulsa focus group said that they obtain most of their health-related information from newspapers.

### **E. VISION**

When asked how often they visit an eye care provider, most respondents said that they go every three months, every six months, every year, or every other year. Other participants said that they go to the eye doctor every three to four years. Two extreme responses respectively included four and five years prior to the focus groups while another participant said that they could not recall because it had been so long. Apparently, respondents with diabetes were more likely to visit the doctor every three to six months. This was especially frequent among those participants who said that they are insured through Kaiser Permanente. A participant from the San Francisco group explained,

*"(I see an) ophthalmologist every other month. I belong to Kaiser, and everything is linked you know. When they discovered diabetes, then I had to go have (my) eyes checked (regularly)..."*

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An overwhelming majority of participants said that they have a regular eye care provider. Many of the participants said that they have a regular eye care provider due to past eye-related surgery(s) and/or diagnosed eye disease such as cataract, diabetic retinopathy, or glaucoma. However, a couple of the participants with a diagnosed eye disease were not familiar with that disease, (e.g., causes, affects, symptoms). For instance, one Sioux Falls participant said that he had not heard the term “diabetic retinopathy” prior to the focus group. He continued to say, “I’ve been to the doctor, and he just tells me (to) stay off the sugar and the candy bars and eat a good diet.”

Most participants said that they have their eyes dilated on a regular basis. Again, an overwhelming majority of participants said that they have their eyes dilated whenever they visit their eye care provider. Although a majority of participants in all of the focus groups said that they have their eyes dilated regularly, most were not able to clearly articulate the purpose of a dilated eye exam. Only a couple of the participants from all of the focus groups in total were able to partially explain the purpose of a dilated exam.

*“The dilation is so that they can see in to make sure that the retina and the macula (are) healthy.” (Sioux Falls, SD)*

*“Well, that’s the way for the doctor to see behind your eye, and it’s very important to have that (so that the doctor) can look for different kinds of eye diseases.” (San Francisco, CA)*

A great majority of participants said that vision loss is part of the aging process. Very few participants said otherwise. When initially asked what they know about vision, participants said that it gets worse as they get older.

*“As you get older, it becomes a concern, especially when you do night driving. I noticed a difference in night driving over the last five years.” (Kansas City, MO)*

*“It’s not as strong as it was when you were younger.” (Boston, MA)*

*“I know that vision is important because, as you reach a certain time in your age, your vision changes a lot.” (Chicago, IL)*

*“I can’t see as well as I used to. That’s the first thing that comes to mind. I had to buy a magnifying glass. That bothers me. I can’t do some of the finer point things (e.g., knitting, crocheting, etc.) that I have done in the past.” (Boston, MA)*

*“I used to be able to say I could see anything. Now it’s getting less and less that I can see. It worries me.” (Portland, OR)*

Some participants said that they did not associate vision loss with the overall aging process. As such, participants suggested that vision loss could be prevented by regular exams and a proper, nutritious diet. Tulsa older adults overwhelmingly expressed this perception. Other participants said that hereditary or genetic-related vision loss is not preventable, however. A couple of participants in the Boston and Tulsa focus groups suggested that teaching adolescents and young adults proper eye care will prove to be effective against vision loss when they get older.

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Participants in several of the focus groups agreed that while sight is important, eye care is not a top priority until seeing becomes difficult. Many participants said that in their personal experience, vision and/or the thought of vision loss becomes an issue once they are unable to read.

*“I think it’s the one sense that I would hate to have to do without. You use it so much and you’re not even aware of how it would be if you couldn’t. Because I like to read. That would just completely cut that out.”* (Kansas City, MO)

*“How horrible it would be not to be able to read anymore. So taking care of your vision is vital.”* (Boston, MA)

*“I used to read constantly. Now I can’t do it. I read for about half-an-hour and my eyes start tearing – tears come out of my eyes.”* (Chicago, IL)

*“My eyes get tired when I read.”* (Chicago, IL)

A few participants also mentioned that they have an ultimate fear of not being able to see their children and/or grandchildren because of vision loss. However, the loss of night vision was an immediate concern among most participants. They said that if they lose their vision they would not be able to drive themselves. Consequently, they would lose their independence and be forced to rely on others. Several participants mentioned that driving at night had already become an obstacle.

*“...when I was young, I could drive all night. Nothing would bother me. I just thought (not being able to drive at night) was part of aging.”* (Sioux Falls, SD)

*“I wear glasses but I hate to wear them. I got to when I drive, otherwise I see four headlights coming at me. I’ll tell you, night driving—and I drive a semi—the big truck up in Montana. With the eyes going, I’m smart enough not to drive at nighttime now. Dusk is it.”* (Sioux Falls, SD)

*“...at night the lights do a job on my eyes. So I have just come to the conclusion that I’m not going to drive at night because of the glare.”* (Boston, MA)

*“As you get older, it becomes a concern, especially when you do night driving. I notice a difference in night driving over the last five years.”* (Kansas City, MO)

*“I don’t drive on the freeway at night...fear that I’m getting older.”* (San Francisco, CA)

Other participants said that specific diseases such as cataract, diabetic eye disease, glaucoma, and macular degeneration come to mind when asked about vision. As one Chicago focus group participant explained,

*“All I know is that diabetes affects (vision). I have three children who are diabetic. Just this past year, found out that they (are) diabetics. And one of them has had to see an eye doctor. And he’s got a very strong (eyeglass) lens. (Diabetes) really affected his eyes.”*

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When asked about age-related vision loss, many participants specifically mentioned cataracts or glaucoma. For instance, one Portland focus group participant replied, “I think about the diseases. I think about glaucoma.” Another participant in the same group said, “I think of cataracts.” A San Francisco focus group participant expressed the same sentiment. “Vision at this age means cataract.”

Again, there was some confusion among participants when asked about specific eye diseases and/or disorders. For example, most participants in the Sioux Falls focus groups and some participants in the Chicago and Boston focus groups said that they had never heard the term diabetic retinopathy before. However, participants in the Oklahoma focus groups said that they were quite familiar with the term diabetic retinopathy as many of them are people with diabetes. Therefore, many of the Tulsa older adults emphasized a proper and nutritious diet to avoid vision-related problems.

In general, the most commonly known term among older adult participants was “cataract” since an overwhelming majority of participants have or had cataract at some point in their older adulthood. In fact, a participant in the Oklahoma focus group mentioned, “(the doctor) said I had a secondary cataract, and (he) wanted to take it off. So I went down yesterday and they took it off.”

Glaucoma was also well known among participants. Participants who mentioned the term ‘glaucoma’ in relation to age-related vision loss said that they knew eye pressure was a cause. When asked to describe glaucoma many participants often responded with the word “pressure,” as one Portland participant explained glaucoma as “undue pressure in the eyeball.”

Macular degeneration was not as well known as cataract and/or glaucoma. A few participants in the San Francisco groups were somewhat familiar with the term. For those participants who were familiar with the term, they explained that the disease can cause one to lose their vision. One participant in the focus group was able to verbally illustrate macular degeneration.

*“Macular degeneration, you lose your central vision... With macular degeneration, the screen becomes smaller and smaller and smaller.”*

Out of all the focus group participants, only two mentioned low vision as an age-related vision disorder. The moderator was often met with silence when older adults and health care providers were asked about their familiarity with the term “low vision.”

When asked what do they typically do when they encounter problems with their vision, many participants said that they schedule an eye exam or call their eye care provider. Other participants said that they are not able to schedule an eye exam due to insurance restrictions. As such, a few participants said that they use eye drops while a couple of other participants said that they use ice or a cold compress. One Boston participant explained, “...I’ll take the ice cube and I’ll hold it there to make me see better.”

## F. PATIENT VISION CONCERNS

In terms of vision concerns, the health care providers’ responses were similar to those of the older adult population. Health care providers said that patients typically complain about their inability to read small print or watch TV. Participants said that patients also voice concerns

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about diabetes-related vision complications, cataract, and glaucoma. As one Chicago health provider indicated, "...what I see mostly are the diabetic patients who are having the greatest eye trouble right now." Also, patients' inability to drive themselves was also mentioned.

*"Well, ultimately everybody gets cataract surgery now, you know. (Around) 75 it comes up. So, when you've always had glasses or when you're driving all the time, that's a major threat to your independence." (San Francisco, CA)*

*"I had a patient yesterday that told me, 'I need assistance going downtown because one eye is failing; I'm afraid I'm going to be hit from the blind side.' So, I think vision concerns (older adults) have tend to keep them home increasingly as much as their mobility problems." (San Francisco, CA)*

*"These people have already been retired, and they spend most of their time at home, alone, or with another spouse maybe. What can they do if they can't drive, they can't read, they can't do the crafts they enjoy? It's really frustrating to them to feel like they're really starting to decline in their leisure activities, as well." (Chicago, IL)*

Minneapolis health care providers said that the older adults whom they serve often lose or break their glasses and typically have to wait a year before they can get replacements. A few Chicago health care providers also said that their patients complain about the quality of vision care provided by their eye care provider or the overall health care system.

*"...and getting their main needs heard. Often I see that even if (older adults) do have the ability to express their needs, being taken as seriously as they need to be taken, instead of (ignoring them)... because of lack of funds. It's much easier I guess, for the current health system just to kind of pat (older adults) on the head and say, well, you know, you are getting older." (Chicago, IL)*

*"Well, there's a lot of prejudice too. (The other participant) was talking about dementia. Doctors, it's like you're old, and you're confused by dementia and it's not always dementia." (Chicago, IL)*

*"Their age alone will define them as well. Clients of mine have been told that because their glasses broke, (the insurance company) is not going to pay for their glasses for the next three years...It's something obscene. And (older adults) are not valued because they're old anyway. They're not going to work or anything, so they're not going to worry about it, either, and there's no way they can make an appeal." (Chicago, IL)*

### **G. KNOWLEDGE OF AGE-RELATED VISION CARE**

When asked what they know about age-related vision care, the majority of health care providers said that vision becomes increasingly impaired as one gets older. A Portland health care provider explicitly expressed this sentiment as he commented, "even without a disease process, it's a general fact that the aging (process) causes loss of acuity in sight. And as (the aging process) goes on, (vision) becomes worse."

Similar to the older adult population, an overwhelming majority of health care providers associated age-related vision care with diseases such as cataract and glaucoma. As one Portland

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health care provider stated, “glaucoma and cataracts are such a big thing... elder people are having to deal with the glaucoma and the cataracts and their limited vision.” Other participants mentioned tunnel vision as another age-related vision care issue. However, very few participants in health care provider focus groups linked tunnel vision to a specific eye disease or disorder.

All of the service providers in the Chicago focus group were familiar with the terms cataract and glaucoma while very few of the Portland and San Francisco service providers were familiar with the terms. In fact, when asked to describe glaucoma, one San Francisco health care provider responded, “it’s an eye disease.”

A few participants in the Chicago and Portland focus group were familiar with the terms age-related macular degeneration and low vision. Those health care providers who were familiar with the various terms and symptoms said that they had to study eye diseases and disorders as part of a school curriculum. For example, one Portland health care provider was able to accurately define all of the terms presented by the moderator because he had studied ophthalmologic conditions while attending graduate school.

Service providers in the Chicago and Portland focus groups were able to articulate the symptoms of age-related macular degeneration and glaucoma. Ironically, most participants in the Portland focus group were not able to articulate symptoms, although all of them had heard the term. Symptoms relating to diabetic retinopathy and low vision were unknown among most participants.

### **H. OLDER ADULT EDUCATION**

When asked about what concerns them most about their vision, older adults said that they feared a loss of independence. More specifically, older adults said that not being able to drive or read would be devastating to them. A couple of participants mentioned poor eye care as a concern.

As conveyed during the health care provider focus groups, many participants in the older-adult focus groups said that their respective eye care provider was less than responsive when a concern was presented to the eye care provider. Some participants said that they do not ask any questions if their eye care provider does not detect any problems during an exam. One Sioux Falls participant said that he didn’t ask questions as he commented, “I just figured it was part of getting old.”

Older adult participants said that they would like to receive more information detailing their respective eye conditions and/or concerns. More specifically, some participants said that they would like to get more information that defines eye-related jargon. This information was especially important to participants as several of the older adults mentioned that their doctor does not take time to explain specifics to them. However, older adult participants said that they want the information to be kept short and simple. One San Francisco older adult explained, “...sometimes I read some (health-related information) and it’s so technical that I don’t even know what I’m reading.”

When asked about the quality of current information provided to them, many respondents said that the information was very general. As such, older adults said they would like more specific information on the causes and symptoms of various eye diseases and/or conditions. Along the same vein, older adults conveyed that they would like more prevention information for various

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eye diseases and/or conditions. Other participants said that they would like step-by-step directions that instruct a person on what they should do if they encounter any difficulties and/or symptoms concerning their vision.

*“...Just to know at what stage of a problem I might have, and what I may expect to happen, and if something happens, what am I to do.”*

### I. EDUCATION

In terms of education, service providers said that they would like to know the symptoms of various eye diseases and conditions so that they can provide adequate service to their patients. Service providers said that this information would enable them to help their patients obtain appropriate resources and/or services. Some participants suggested conferences and/or training to satisfy this need. A couple of Chicago and Portland participants suggested that a few general screening questions could be developed for health care providers.

*“...Just basic questions, a few questions about your vision: ‘When was the last time you had your vision checked? How is your vision? Do you have any (vision-related) problems?’ A few questions. That’s it.”*

*“...But this should be part, I think, of when you go in to a doctor, and you’re a certain age... You can ask (this) question, ‘Are you having trouble with your vision?’”*

### J. MATERIALS DEVELOPMENT

Older adults said that they would prefer to receive information in the form of DVD, brochures, mail, pamphlets, and/or video. Of course, participants advised that print materials should use large fonts. A couple of participants said that they would like to receive information in the form of a phone call from a nurse. A couple of older adults suggested that workshops or seminars could be held in local libraries to allow community residents to ask questions. Several Boston older adults suggested that materials be culturally relevant to draw the attention of the target audiences.

Several health care providers suggested that talking books would also be helpful to the older adult population as many of them have trouble seeing print. In terms of distribution centers for materials, participants suggested churches, hospitals, senior citizen centers, and workshops.

Service providers said that portable exhibits would be quite beneficial, as they would enable onsite workshops and seminars in various settings including shopping malls and doctors’ offices. While some service providers thought that CD-ROMs would be useful to the older adult population, other health care providers did not agree. In fact, all of the participants in the San Francisco focus group said that they didn’t think CD-ROMs would be useful. Those who did not agree said so because of financial constraints faced by older adults (i.e., they would not be able to afford a computer).

Many older adults agreed with the health care providers that opposed the development of CD-ROMs for the older adult population. Although many of the older adults said that they own computers, very few older adults said that they actually use them. Several older adult

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participants in the Chicago and Kansas City focus groups summarized the sentiments of the older adult population in terms of using computers for health-related information:

*“We’re not computerized. It’s true. (The computer) is there, but I’d rather read (a brochure) than go to the computer. To me, it’s too confusing to go in there. I’d rather get a book and read it.” (Chicago, IL)*

*“We’re not the computer generation.” (Chicago, IL)*

*“We’re not the computer age. That’s it. You’ve got it.” (Chicago, IL)*

*“That computer and the color television and all that stuff...the quickness of them, to me it’s really scary.” (Kansas City, MO)*

## VI. SUMMARY

Although many participants admitted to having ailments such as arthritis, cancer, diabetes, or high blood pressure, most said they felt good. Participants were concerned about depression; payments for medications; poor nutrition; hearing, sight, and memory loss; and quality of life.

Regarding frequency of appointments with eye care providers, most participants said they have one every few months, every year, or every other year. Only a few participants went longer without a visit to an eye care provider. A majority of participants stated they have their eyes dilated on a regular basis, although most of them could not explain the purpose of a dilated eye exam.

Many participants experienced loss of night vision, and feared a loss of independence due to not being able to drive because of vision loss.

Focus group participants also said that the NEI should continue to provide older adults and health care providers with as much information on vision care as possible. In general, older adults and health care providers said that the NEI should take efforts to make vision a top priority. Most participants within the two populations agreed that vision is an age-related concern. However, older adults and health care providers said that older adults should be provided with appropriate vision and eye care.

Health care providers suggested conferences, trainings, and workshops for persons who work with the older adult population to spread information about eye diseases and disorders. Health care providers also stated that they would like to have brief screening questions developed for the general health care field so that they know what to ask if and/or when they encounter a patient or client that is experiencing eye related problems.

Health care providers also stressed the need for information that explains the symptoms and causes of various eye diseases and/or conditions. Health care providers suggested pamphlets and brochures to satisfy this need. For the older adult population, health care providers liked the idea of portable or tabletop exhibits. They also suggested using shopping malls and churches as a venue to educate the older adult population on vision care.

**FINAL OLDER ADULT NEEDS ASSESSMENT  
FOCUS GROUPS REPORT**

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While some participants in the older adult focus groups were vague while saying that they just want more brochures, other participants were more specific. Many older adults, similar to health care providers, said that they would like a greater amount of information on prevention and the treatment of specific symptoms. In whole, participants would like a step-by-step guide on what to do about certain symptoms or how to prevent developing symptoms altogether.

Older adults and health care providers opposed the use of CD-ROMs to distribute health-related information to older adults. Although many older adults said that they have access to a computer, the majority of older adults said that they do not use the computer. The development of brochures and/or pamphlets was highly recommended among older adult participants.

## VII. RECOMMENDATIONS

The table on the following page summarizes the recommendations based on the feedback of focus group participants. Recommendations are categorized by material type, content, format, and preferred method of distribution. Miscellaneous recommendations are also included.

	<b>Older Adult Population</b>	<b>Health Care Provider Population</b>
<b>Material Types</b>	<input type="checkbox"/> Brochures <input type="checkbox"/> Pamphlets	<input type="checkbox"/> Brochures <input type="checkbox"/> CD-ROMs
<b>Material Contents</b>	<input type="checkbox"/> Cause(s) of respective eye disease or condition. <input type="checkbox"/> Step-by-step instructions detailing how to treat and/or manage the respective eye disease or condition. <input type="checkbox"/> Symptom(s) of respective eye disease or condition.	<input type="checkbox"/> Cause(s) of respective eye disease or condition. <input type="checkbox"/> Step-by-step instruction detailing how and where to refer patient. <input type="checkbox"/> Symptom(s) of respective eye disease or condition.
<b>Material Format</b>	<input type="checkbox"/> Limited jargon and/or medical usage <input type="checkbox"/> Simple words and/or terms	<input type="checkbox"/> Simple words and/or terms
<b>Material Distribution and Eye Health Education Venues</b>	<input type="checkbox"/> Churches <input type="checkbox"/> Portable Tabletop Exhibits <input type="checkbox"/> Shopping Malls	<input type="checkbox"/> Conferences <input type="checkbox"/> Training <input type="checkbox"/> Workshops
<b>Miscellaneous</b>		<input type="checkbox"/> One to three basic, screening questions

## **Appendix A**

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### **Participant Screeners for Older Adults and Service Providers**

## Screener for Low Vision Needs Assessment of the Older Adult Population

### A. Recruiting Goals

- Participants shall be adult of at least 65 years of age.
- Each group should be composed of equivalent numbers of men and women.
- Persons who work, have worked, or have a family member who is employed in the vision care industry shall be excluded.
- Persons who work or have worked or have a family member who is employed by the National Eye Institute or any state or local agency responsible for eye care shall be excluded.
- Participants shall not have participated in a focus group or other qualitative research study over the past year

### Screening Questions for Elderly Persons

Hello Mr./Ms. (if known), my name is \_\_\_\_\_ and I am calling from\_\_\_\_\_. We are working with a research firm on a project to learn more about health concerns among the elderly. Could I ask you a few short questions?

1. Determine gender.
  - Male
  - Female
2. Could you tell me which of these age groups you belong to?
  - Under age 65 ---- **terminate**
  - Age 65 or over ---- continue
3. What is your ethnic background?
  - Asian American
  - Black/African American
  - Hispanic/Latino
  - White/Caucasian
  - Pacific Islander
  - American Indian

Note: **Terminate if other than the specific ethnic target population being recruited for the location.**

4. Have you or any member of your immediate family ever worked for the National Eye Institute or any other federal, state or local agency that is responsible for eye care?
  - No---- continue
  - Yes-----**terminate**

5. Have you or any member of your immediate family ever worked in the eye care industry?
- No ---continue
  - Yes----- **terminate**
6. In the past year have you participated in any focus groups, mock juries, or other research studies other than telephone interviews?
- No---continue
  - Yes----**terminate**
7. We would like you to participate in a discussion with one of our staff to talk about eye health concerns you have and how they affect your daily activities. The focus group will last about 2 hours. You will be paid \$50 for your participation plus transportation costs including taxicab fare. Would you be willing to participate in this focus group?
- Yes---continue
  - No----terminate**
8. I would like to send you a confirmation letter and directions to the facility. In order to do so, could you please tell me your mailing address and give me a phone number where you can be reached:

NAME: \_\_\_\_\_

ADDRESS:\_\_\_\_\_

CITY:\_\_\_\_\_STATE\_\_\_\_\_ZIP-CODE\_\_\_\_\_

PHONE: (H)\_\_\_\_\_

(W)\_\_\_\_\_

DATE OF FOCUS GROUP\_\_\_\_\_TIME\_\_\_\_\_

We are inviting only a few people, so it is very important that you notify us as soon as possible if for some reason you are unable to attend. Please call (insert name of recruiter) at (insert telephone number) if this should happen. We look forward to seeing you on (insert date) at (insert time). If you use reading glasses or assistive devices, please bring them with you to the focus group.

## Screener for Service Providers

### A. Recruiting Goals

- Each group should be composed of equivalent numbers of men and women.
- The participant should have experience serving the 65-year and older population.
- Persons who work or have worked or have a family member who is employed by the National Eye Institute or any state or local agency responsible for eye care shall be excluded.
- Participants shall not have participated in a focus group or other qualitative research study over the last six months.

### Screening Questions for Service Providers

Hello Dr./Mr/Mrs. (if known), my name is \_\_\_\_\_ and I am calling from\_\_\_\_\_. We are working with a research firm on a project to learn what service providers' needs are in working with the elderly population. Could I ask you a few short questions regarding this issue?

1. Determine gender.
  - Male
  - Female
  
2. Please tell me if you are a/n
  - Geriatrics program staff member
  - Health educator
  - Home health care or assisted living provider
  - Medical doctor
  - Nurse
  - None of the above----**TERMINATE**
  
3. Do or have you worked with the elderly population—ages 65 and above?
  - Yes-----continue
  - No-----**Terminate**
  
4. Have you or any member of your immediate family ever worked for the National Eye Institute or any other federal, state or local agency that is responsible for eye care?
  - No---- continue
  - Yes-----**Terminate**
  
5. In the past six months, have you participated in any focus groups, mock juries, or other research studies? [**Participation in telephone surveys is allowable.**]
  - No----continue
  - Yes----**Terminate**

6. We would like you to participate in a discussion with one of our staff to talk about your needs in working with the elderly population. The focus group will last about 2 hours. You will be paid **\$300** for your participation. Would you be willing to participate in this focus group?

Yes---continue

No----**Terminate**

7. I would like to send you a confirmation letter and directions to the facility. In order to do so, could you please tell me your mailing address and give me a phone number where you can be reached:

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE \_\_\_\_\_ ZIP-CODE \_\_\_\_\_

PHONE: (H) \_\_\_\_\_

(W) \_\_\_\_\_

EMAIL ADDRESS \_\_\_\_\_

CELL PHONE: \_\_\_\_\_

DATE OF FOCUS GROUP \_\_\_\_\_ TIME \_\_\_\_\_

*We are inviting only a few people, so it is very important that you notify us as soon as possible if for some reason you are unable to attend. Please call (insert name of recruiter) at (insert telephone number) if this should happen.*

## **Appendix B**

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### **Moderator's Guides for Older Adults and Service Providers**

# Moderator's Guide

## Older Adult Population

### I. Welcome, Introductions, and Opening

#### A. Welcome

Good afternoon, my name is (moderator's name) and I will be your moderator for this session. I am employed by a management consulting firm located just outside of Washington, DC. Our client is interested in vision care concerns among older adults (65 years and older). I want to let you know that I am not an expert in vision care, rather I am an independent moderator trained to facilitate our discussion.

#### B. Introductions

Before we begin let's introduce ourselves. As I mentioned I am \_\_\_\_\_. My job is to ask you questions and, if needed, to ask you to clarify your response. It is important for you to know that there are no right and wrong answers here. We just want to get a better understanding of your vision care concerns and how and where you learn about vision care.

Let's begin on my left and move around the table. Tell me your name and why you agreed to participate in this focus group today. Thank you.

#### C. Ground Rules

*Now I would like to talk a little bit about our ground rules for today's discussion. Ground rules are our guidelines for operating today so that we can complete our task in a manner that is respectful of everyone and provides all of you with the opportunity to express your thoughts safely and confidentially.*

- You have been invited here to offer your views and opinions.
- **Everyone's** participation is important.
- Please speak **one** at a time.
- There are **no** right or wrong answers.
- It's **okay** to be critical. If you dislike something you hear, it's okay to disagree but be willing to offer your own views and opinions.
- This session will be **audio [and video] taped**. This allows us to capture everything that is being said today, which we will need to write our report to our client. (If there is a one-way mirror mention that there are observers in the next room and mention who the observers are and why they are behind the mirror. Also mention where the audio equipment is located if it is not obvious.)

- All of your answers will be **confidential**, so feel free to say exactly what is on your mind. Nothing will be attributed to any particular person in our report.
- If anyone needs to use the rest room, they are located [specify]. There is no need to stop the discussion.

Do you have any questions before we get started?

## II. General Health

*Let's begin by talking about your health.*

- How do you rate your general health?
- How often have you seen a doctor in the past year?
  - Probe:
    - What type of doctor(s) did you see?
- Where do you get information for health issues?
  - Probe:
    - TV, radio, newspaper, magazines, friends, and/or Internet.
    - How many of you use a computer or access the Internet for health information?
      - What type of information do you seek on the Internet?

## III. Vision

*Now I'd like to talk more specifically about vision.*

- When was the last time you had your eyes examined? (past year, 1-2 years, more than 2 years)
  - Probe:
    - By whom? (optometrist, ophthalmologist)
- Whenever you visit the optometrist or ophthalmologist, do you have your eyes dilated?
  - Probe:
    - How often? (once a year, once every two years-?)
- What do you know about vision?
  - Probe:
    - What comes to mind when I ask you about your vision?
    - What do you think of when you hear the word vision?
- What do you think of when you hear "age-related vision problems?"
  - Probe:
    - Which vision problem(s) come to mind (i.e., age-related macular degeneration, cataract(s), glaucoma, diabetic retinopathy, low vision)?
    - How many of you have age-related vision conditions(s)?

- How did you learn that you had this specific vision condition?
- What concerns, if any, do you have about your vision?
  - Probe:
    - What are you doing about your concerns?
    - Have you shared your concerns with anyone (e.g., eye doctor, family, friend)?
- What do you do when you have problems with your vision?
  - Probe:
    - Do you seek help if you have a problem with your vision? If yes...
      - Do you go to the doctor? If yes, what kind of doctor?
      - Talk to family or friends?
      - Try to get information about eyes? – If yes, what type of information do you look for? Where do you get this information?
    - If no, do you just cope? What does that mean?
    - How do you take care of your vision (eye sight)?
- For those of you who have problems with your vision, how has this affected your day-to-day activities?
- What do you think of when I say “vision loss”?
- Do you think that vision loss can be prevented?
  - Probe:
    - How can people prevent vision loss (i.e., getting their eyes checked, surgery, diet, vitamins, protective eye wear)
- Do you associate vision loss with aging?

#### **IV. Older Adult Education**

- What concerns you most about your vision? (The possibility of losing your vision?)
- What types of conversations have you had with your eye care professional about any functional problems you may have in carrying out your daily routines?
  - Probe:
    - What kind of information would be helpful to you?
    - In what format do you like to receive information about your vision and devices that may help you, family members, and/or friends (e.g., verbally from a health care provider, from a brochure/pamphlet, audio cassette, video tape)?
- What types of information does your health care professional offer you about vision care?
  - Probe:

- Who provides you with this information (i.e., primary care provider, eye care professional, home health aid, staff at senior center, nurse)?
  - Is the information provided verbally or in writing?
  - How helpful is the information provided to you?
- What obstacles have you or a family or friend encountered when trying to find out information about vision care or products that may assist you in your daily living?
- How would you best describe your needs for further education about your vision?
- Probe:
    - How would you like to receive this information?

**Moderator:** Before we end our session today I want to check with my client and see if there is anything else I need to ask or clarify. I'll be back in a minute or two.

## V. Summary

Before we close this session, I would like to tell you that our client is the National Eye Institute (NEI), which is part of the National Institutes of Health located in Bethesda, Maryland. The NEI provides vision care information to consumers such as you about the various vision conditions including glaucoma, diabetic retinopathy, cataract, age related macular degeneration, and low vision.

- If there was one thing that the NEI could do regarding vision care for older adults what would that be?

On behalf of the NEI, I wish to thank all of you for your input today.

# Moderator's Guide For Service Providers

## I. Welcome, Introductions, and Opening

### A. Welcome

Good afternoon, my name is (moderator's name) and I will be your moderator for this session. I am employed by a management consulting firm located just outside of Washington, DC. Our client is interested in learning about what you know about age-related vision concerns among older adults (65 years and older). I want to let you know that I am not an expert in vision care, rather I am an independent moderator trained to facilitate our discussion.

### B. Introductions

Before we begin let's introduce ourselves. As I mentioned I am \_\_\_\_\_. My job is to ask you questions and, if needed, to ask you to clarify your response. It is important for you to know that there are no right and wrong answers here. We want to learn more about age-related vision care information regarding older adults that you come in contact with in your job.

Let's begin on my left and move around the table. Tell me your name and how long you have worked with the older adult population. Thank you.

### C. Ground Rules

*Next, I would like to talk a little bit about our ground rules for today's discussion. Ground rules are our guidelines for operating today so that we can complete our task in a manner that is respectful of everyone and provides all of you with the opportunity to express your thoughts safely and confidentially.*

- You have been invited here to offer your views and opinions.
- **Everyone's** participation is important.
- Please speak **one** at a time.
- There are **no** right or wrong answers.
- It's **okay** to be critical. If you dislike something you hear, it's okay to disagree but be willing to offer your own views and opinions.
- This session will be **audio [and video] taped**. This allows us to capture everything that is being said today, which we will need to write our report to our client. (If there is a one-way mirror mention that there are observers in the next

room and mention who the observers are and why they are behind the mirror. Also mention where the audio equipment is located if it is not obvious.)

- All of your answers will be **confidential**, so feel free to say exactly what is on your mind. Nothing will be attributed to any particular person in our report.
- If anyone needs to use the rest room, they are located [specify]. There is no need to stop the discussion.

Do you have any questions before we get started?

## II. About You

*To get started, let's go around the table so everyone can tell us a little about their occupation and clients they work with.*

- Please tell us—
  - What is your job title?
  - How long have you held this position?
  - What are your overall job responsibilities?
- What types of health issues do you hear about from the older adults you serve?
- In your position, how often do you interact with older adults/provide care for older adult clients?
- Do you ever talk to older adults about their vision concerns that may affect their daily routines?
  - Probe –
    - How do you start this type of conversation?
    - Describe the vision care concerns you hear about.
  - Where is the best place for you to receive information related to the vision care concerns of the older adult population?
    - Probe –
      - Meetings, conferences, workshops, journals, distance learning?

## III. Your Knowledge about Vision Care

*Next in our discussion, let's discuss vision care.*

- What do you know about age-related vision problems?
  - Probe:
    - How did you learn about these problems?
- In general, how familiar are you with the following—
  - Probe for—
    - Age-Related Macular Degeneration (symptoms, causes)
    - Cataract (symptoms, causes)

- Diabetic Retinopathy (symptoms, causes)
  - Glaucoma (symptoms, causes)
  - Low Vision
- How did you learn about these vision conditions (i.e., AMD, cataract, diabetic retinopathy, glaucoma, low vision)?
  - What types of vision care information do the older adults you interact with ever ask for?
  - What do you think would make it easier for you to provide information about vision to the older adults that you interact with?
  - What suggestions can you offer about how to make vision a priority for people such as yourself who interact on a regular basis with the older adult population?

#### **IV. Vision Care Materials for Older Adults**

*Our client has developed a variety of materials about vision for consumers. Information is provided in brochures, fact sheets, pamphlets; as well as CD-ROMs, and portable exhibits.*

- Thinking about the older adults you work with and their vision care concerns, what type or types of materials do you think would be helpful to them?
  - Probe:
    - In what format (i.e., print, video, audio, CD-ROM)?
    - Do you think the older adults you work with would be able to access information from a CD-ROM if they were given one?
    - What information should be included – what topics?
- What are your thoughts about providing vision care information on a portable exhibit that would be displayed in your place of work? [Note: a portable exhibit could be something like a tri-fold board on a table, information placed on an easel, wall hangings/posters, a computer with a CD-ROM that a person could use, or even a continuous video loop shown on a television.]
  - Probe:
    - What types of age-related vision health information would you suggest this display include? (For example: assistive devices; pictures of what a person with age-related macular degeneration, cataracts, glaucoma, diabetic retinopathy sees; a diagram of the eye; fact sheets; local resources.)
- What are your thoughts about providing vision care information to older adults on a computer-based program?

#### **V. Education**

- Based on your own knowledge of the previously discussed vision care and older adults, what do you need professionally to help you enhance your ability to

educate yourself and older adult populations that you come in contact with about vision care?

- Probe:
  - Brochures, pamphlets, videos?

- How would you like to receive this information?

**Moderator:** Before we end our session today I want to check with my client and see if there is anything else I need to ask or clarify. I'll be back in a minute or two.

## **VI. Closing**

Before we close this session, I would like to tell you that our client is the National Eye Institute (NEI), which is part of the National Institutes of Health located in Bethesda, Maryland. The NEI provides vision care information to professionals and consumers.

- Is there anything else that you would like the NEI to know regarding the types of vision care information professionals who work with older adults need?
- Finally, do you have any additional suggestions how the NEI can make vision a priority for those working with the older adult population?

On behalf of the NEI, I wish to thank all of you for your input today.